



RESEARCH

Medical information and consent for cancer patients

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Abstract

The way people with cancer access health information and the impact such knowledge has on decision-making is a matter of crucial interest in this group. This research intends to promote a critical reflection on personal, professional values and of society in general; to identify underlying ethical principles to decision making; to analyze the professional relationship with the sick person; to characterize the decision making and quantify the information provided to users. It is a quantitative, exploratory study with application of Easy-Care questionnaire, and QLQ – INFO25 in a sample of 20 people with cancer. It was observed deficits in adequate information to the needs of people with cancer in the fields of self-management of the disease; use of certain services (physical therapy, psychology) and the influence of the disease/treatment in social and family environment.

Keywords: Information. Health communication. Personal autonomy. Informed consent. Decision making. Neoplasms.

Resumo

Informação médica e consentimento de pessoas com câncer

A forma como pessoas com câncer acedem à informação de saúde e o impacto deste conhecimento na tomada de decisão constituem questão de interesse fulcral para este grupo. Esta pesquisa objetiva promover reflexão crítica sobre valores de natureza pessoal, profissional e da sociedade em geral; identificar princípios éticos subjacentes à tomada de decisão; analisar a relação profissional-pessoa doente; caracterizar a tomada de decisão; e quantificar a informação fornecida aos usuários. Trata-se de estudo quantitativo e exploratório, realizado mediante aplicação de questionário Easy-Care e QLQ – INFO25 em amostra de 20 pessoas com câncer. Verificou-se déficits na informação adequada às necessidades das pessoas com câncer nas áreas da autogestão da doença, do uso de determinados serviços (fisioterapia, psicologia) e da influência da doença/tratamento nos ambientes social e familiar.

Palavras-chave: Informação. Comunicação em saúde. Autonomia pessoal. Consentimento livre e esclarecido. Tomada de decisões. Neoplasias.

Resumen

La información médica y el consentimiento de las personas con cáncer

La forma en que las personas con cáncer acceden a la información sobre la salud y el impacto que este conocimiento tiene en la toma de decisiones constituyen un asunto de interés fundamental para este grupo. Esta investigación tiene como objetivo promover la reflexión crítica sobre valores de índole personal, profesional y de la sociedad en general; identificar los principios éticos subyacentes a la toma de decisiones; analizar la relación entre el profesional y el paciente; caracterizar la toma de decisiones y cuantificar la información facilitada a los usuarios. Se trata de un estudio cuantitativo, exploratorio, realizado por medio de la aplicación del cuestionario Easy-Care y QLQ – INFO25 en una muestra de 20 personas con cáncer. Se verificó un déficit en la información adecuada a las necesidades de las personas con cáncer en las áreas de la autogestión de la enfermedad, de la utilización de ciertos servicios (fisioterapia, psicología) y de la influencia de la enfermedad/tratamiento en el entorno social y familiar.

Palabras clave: Información. Comunicación en salud. Autonomía personal. Consentimiento informado. Toma de decisiones. Neoplasias.

Declaram não haver conflito de interesse.

Cancer is currently one of the main concerns in World Health, evidencing the trend of increasing impact. Estimates related to the incidence, mortality and prevalence of 28 types of cancer in 184 countries presented by the International Agency for Research on Cancer¹ revealed in 2012 the total of 14.1 million new cases and 8.2 million deaths associated with this pathology. Based on population aging, a 13.7% increase in new cases in the European Union and 12.6% in Portugal is expected for the next decade.

Along with this mortality there is the whole process of illness, acceptance, mourning, adaptation and the needs of the people who suffer from it and of people close to them, namely the informal caregivers. As health professionals and members of the multidisciplinary team, all those involved in this process should be attentive to these needs, establishing a satisfactory empathic relationship, providing the correct relief of physical symptoms, appropriate spiritual and psychological support, and the provision of adequate information.

Implications of information *versus* communication

Regardless of the area of action of the health professional, all of them base their practice on an interpersonal relationship that requires not only technical knowledge and skills but also a human and humanizing attitude with an ethical elevation². One of the essential aspects of this interpersonal relationship is communication. Communication means much more than the use of words or common vocabulary, but the dynamic exchange of multi-directional, multidimensional and complex information through different sensory channels which allows for sharing attitudes and emotions, thus exceeding the information transmitted just through words³.

Communication (be it verbal and non-verbal) with the patient basically aims to respond to her or his needs to feel understood, informed, supported and accompanied in the process of illness, and to reduce uncertainties, fears and anxieties. Consequently, adaptation to the actual clinical situation is facilitated, the definition of the direction of the patient's life project is aided and achievable goals are redefined². To this end, the professional must have the skills to communicate and inform, that is: 1) to have the capacity to be attentive to the problems of the patient and to capture the emotional, physical and social impact that the disease causes on the person and their family; and

2) tailor information to what the patient wants to know, not forgetting that it is essential to understand how the message was received and interpreted⁴.

There are protocols that can serve as reference and as tools to communicate in these disease situations, especially in cancer. The Spikes protocol is one example of the usefulness of a sequence of substantiated steps, specifically in the preparation (time is fundamental), perception (of what the patient already knows), information (if desired by the patient), knowledge (to produce clarification), attention to emotions (the value of empathy), and cooperation (walking together in face of needs)⁵.

It consists of six steps: 1) professional stance; 2) perception of the sick person; 3) possibility of information exchange; 4) knowledge of the subject matter; 5) ability to explore and emphasize emotions; 6) finalizing the conversation, with strategies and synthesis. The crucial issue is not only of whether the news of the disease is transmitted, but rather how this is done. It is a complex process of listening to doubts, detecting feelings and emotions, sharing pain and suffering, which requires time, harmony and privacy⁶.

In Portugal, information to the patient and his or her family is recognized as a right and responsibility of health professionals, specifically enshrined in the Basic Health Law⁷, the Basic Law on Palliative Care⁸ and the professional codes of health professionals⁹. The creation of the necessary conditions for the proper execution of this right is of particular relevance, since only through adequate and correct information can patients be involved in the course of the disease and consequent decision-making processes. These health processes in their various applications (diagnostic, therapeutic, rehabilitative and preventive) essentially seek actions that modify behaviors, corresponding to needs, impossibilities and possibilities, contingencies and effectiveness.

Especially in situations of proximity to death and in cases where people appear to have severe physical deterioration, health professionals may tend to adopt a paternalistic model of care, take control of the disease situation and perform well-meant but unnecessary care interventions. Assuming that the priorities of the sick person are as valid or more valid than those of the professionals, and considering them in the decision-making process not only increases the degree of satisfaction of the person, but also increases the trust between the professional and the patient.

Plural democracies affirm certain values, such as the inviolability of human life, but at the same time, the notion that, in the context of health care, citizens should be free to refuse certain treatments in the light of the principle of respect for individual autonomy. Thus, it is now possible for any competent sick person to refuse certain treatments, even if it anticipates the moment of his or her death¹⁰.

Informed consent

Ethics in health care can not relegate the right of each citizen to self-determination and respect for one's dignity to the background. The *Nuremberg Code*, in particular, refers to this problem with regard to the ethical imperative of obtaining informed consent. With technological advancement and the resulting evolution of health care, diagnostic and/or therapeutic interventions are now demanded by the caregivers in which everything will have to be clarified for and validated by the patient.

In fact, there is a growing need to clarify sick people about what the health professional will do, why it will be done, what the risks are for the patient, what quality of life they will have, among other things. It is a question of giving patients the possibility to choose freely among the alternatives, on the assumption of the existence of informed consent. All interventions performed in the clinic potentially entail the violation of patient's autonomy. In order for this not to occur, health services and professionals act on the basis of documents and protocols that guide their conduct, namely, the informed consent.

This procedure was first introduced in the United States of America in a decision by a California court in 1957¹¹. The main purpose of the document is to ensure the sharing of power and knowledge between health professional and the patient. More than a permission, the informed consent can be defined as a voluntary and coherent decision made by an autonomous and competent person, based on adequate and deliberate information, to accept more than to reject a proposal of action that will affect her or him¹¹.

For this voluntary and coherent decision-making, health professionals should offer alternatives and discuss choices, taking into account the diverse needs of the patient. The information provided should include, where appropriate, aspects relating to treatments or

other proposed interventions, alternatives and opinions on expectations of success or failure of the suggested procedures. This information will always be subordinated to the principle that it is not possible to guarantee results, but only the use of appropriate and available means¹².

Although signing the informed consent does not imply certainty as to the information provided and its correct understanding, it is required by law for certain interventions. Having said this, health professionals must also be aware that their relationship with the patient must always be based on the truth, and decisions are made for the good of the person in all honesty. To deceive the patient is, in addition to lack of respect, an attitude that limits the action of the professional and the participation of the person in the recovery process.

In fact, it is important to respect the choices of the patient, although we know that there are special circumstances of this situation that need to be discussed. Health professionals should consider whether the information provided was adequate and whether consent to treatment, care or other procedures was free, informed and clarified.

Determining the stage of the disease in which it is still reasonable to attempt to obtain the informed consent is a crucial and widely discussed issue. In the literature analyzed, it is generally agreed that each case should be examined individually. In case the person, after evaluation, does not have the conditions to give consent (not being competent), decisions to be taken by others must be oriented towards the presumed interest of the person concerned.

Only in this way can one respect the sick person, and this must be concretely done. It all starts with the way to approach the person, adopting the name or title with which the patient wishes to be addressed, and following through with the promotion of autonomous behaviors, through appropriate information, assuring the truth and the free decision so that one can assume one's own disease and/or death as completely and constructively as possible. Based on this context, the objectives of this study are: 1) to identify the ethical principles underlying decision making; 2) to analyze the professional-patient relationship; and 3) to quantify the information provided to users with oncological disease of the units of the Baixo Vouga III Health Center Group (Agrupamento de Centros de Saúde Baixo Vouga III - ACES).

Methods

This is a quantitative and exploratory study, and the purpose of the quantitative research method was to contribute to the development and validation of knowledge, and it also offers the possibility to generalize, predict and control the results¹³.

Target population and sample

The target population comprises all the elements that share common characteristics, which are defined by the criteria established for study¹³. In this particular case, the target population comprised users of the Baixo Vouga III ACES diagnosed with cancer and attending the constituent health units. From this sample population a sample was withdrawn from March to August 2012 in three constituent units of the ACES (Family Health Unit João Semana, Murtosa Health Center, Avanca Health Extension), using the technique of sampling by convenience.

Characterization of the sample

In all, there were 20 patients, three males and 17 females. The mean age was 59 years. Men were, on average, older than women. There were 11 people living in the urban area and nine in the rural area, and 50% were married or in stable union. When questioned about the constitution of their household, only 20% of respondents reported living alone, and when questioned about income earned, at least 45% said that it *"is not enough for the needs."*

Regarding formal education, 30% of the sample successfully completed the fourth grade (first half of elementary school), 20% completed the 12th grade (high school) and 15% had a college degree (higher education). Regarding the professional situation of the respondents, 45% of the sample was retired, 35% worked full-time, 5% worked part-time, 10% were unemployed and 5% worked at home. Finally, in relation to the use of care and the provision of care for others, most respondents indicated that they did not use or provide care to others (75% for both).

Data collection instruments

Data were collected according to a preestablished plan: systematic collection of information from participants with the help of the chosen assessment instruments¹³. In the present study, data collection was based on the application of the Easy-Care instrument for sociodemographic characterization of the sample

and the EORTC QLQ - INFO25 questionnaire to evaluate the information provided.

Context and data collection

Data collection began with the researcher's contact with the coordination of the Baixo Vouga III ACES, which collaborated to identify subjects that met the inclusion criteria. The coordination supported research and developed a listing of all users who met these criteria, as well as a first approach to get patients' permission.

During the meeting and before starting the procedures of data collection, participants were informed about the nature and objectives of the research, methods and means by which the study would be conducted, the amount of time necessary for questionnaire application/completion and the confidentiality of data confidentiality, their participation in the study was also requested. Upon affirmative response, participants were asked to sign the informed consent form.

Each questionnaire had instructions on its completion and ensuring anonymity. Completion of the questionnaires took place either in the above mentioned units or during a home visit (in specific cases of incapacity to travel for the patient) during specific consultations, which were previously scheduled for this purpose. Each consultation lasted approximately 60 minutes and was conducted by the researcher.

Ethical issues

For the correct undertaking of this study, applications for authorization of use and application of the questionnaires were addressed to the executive director of the Baixo Vouga III ACES, to the European Organization for Research and Treatment of Cancer and to the Ethics Committee of the Regional Health Administration Center for the collection and processing of information. Information processing did not involve any risk to people, directly or indirectly, since anonymity and confidentiality were ensured. In this sense, at the beginning of the interviews the objectives of the study were exposed and clarified. Participants were assured that the data would be used for research purposes only and not for any other purposes, and the possibility of refusing to answer any of the questions was reiterated.

Data treatment and analysis

Data treatment was performed through the SPSS software, version 20.0 for Windows, and techniques of descriptive statistics were employed.

Analysis and discussion of results

Regarding the diagnosis of the disease, 50% of the sample reported that they got a lot of information and only one person (5%) referred not having received any information. On the extension of the disease, the data obtained are not so conclusive: 35% of the sample reported having receiving some information and 35% of the same percentage reported having a lot of information. Although there are several articles that provide advice on how to report bad news, the guidelines presented differ considerably from one author to another.

Some papers warn of the importance of having family members or other supportive people present, specifically social workers or priests. Other documents emphasize privacy. In the same way, some encourage and others oppose the use of euphemisms. Therefore, the quantity and quality of the information provided to the patient and the way in which this information should be given has been the subject of considerable debate, but there is still no consensus on this issue¹⁴.

When asked about the information received about the possible causes of the disease, 70% reported receiving “no information”; most ensure that the question of genetic component has not even been raised. As to the knowledge that their disease is controlled, 40% of the respondents report “no information”, and one of the aspects considered was the lack of “positive incentives” mentioning aspects that improved since the last consultation and/or treatment. With regard to their examinations, procedures, objectives and results, the data obtained do not allow a conclusive answer, since the percentages for all the response options are similar.

For people with oncological diseases, being optimistic means maintaining a normalcy in life despite the disease, in an attempt to make the illness interfere as little as possible in their quality of life. For some professionals, especially nurses, optimism is the attribute of those who maintain the fighting spirit in the course of illness and its treatment¹⁵. One way of verifying this favorable disposition without giving false hope or conveying the impression that communication is not realistic would be to adopt a cheerful stance in the interaction between the professional and the sick person. In addition, it is necessary to highlight positive aspects of the situation experienced and to reshape the communication made, that is, to change the focus of the conversation from negative facts or situations to something positive¹⁵. In fact, it is possible to make

the patient aware of the worsening clinical situation without this meaning to diminish her/his hope or to leave her/him with no way out by saying that there is nothing to do, in a clear sign of divestment.

The presence of respondents without any type of information regarding the aspects surveyed (about 20%) should be emphasized. Some studies¹⁶ indicate that basing the information provided only on the perception of health professionals to determine the needs of the sick may be not recommended. In fact, there have been consistent findings about how oncological services fail in the communication and information needs of patients. Systematic reviews¹⁷ demonstrate strong evidence that patients feel that they are given insufficient information and that health professionals often have limitations in detecting patients’ needs and the psychological stress brought on by receiving bad news in people with cancer.

Regarding medical treatment, 35% of the respondents stated that they had obtained enough information and 30% considered that they had obtained a lot of information. Still with regard to the treatments and the expected benefit of its accomplishment, 50% of the sample indicated to possess a lot of information. Regarding the possible side effects, eight people (40% of the sample) reported having obtained a lot of information. Regarding the expected effects of the treatment on the symptoms of the disease, the results obtained were not so decisive: 15% of the sample reported not having obtained information on this subject. Regarding the effects of treatment on social and family life, 55% of the sample (11 people) believe they had not received any information. Only 15% of the sample - three people - considered having a lot of information on this topic.

When asked about the information provided regarding the effects of treatment on sexual life, 66.7% of the sample (12 people) said they had not received any information about the fact. The truth is that health professionals, in general and according to an empirical view, provide information in a superficial way, sometimes abrupt and “reduced for lack of time.” This often results in ignoring what the patient wants to know and does not realize if he or she has understood what was transmitted or if any clarification is needed. The consequence of this “non-communication” leads to the omission of the sick person in his illness process, as well as to the impossibility of discussion and choice of therapeutic options, objectively resulting in the negation/

concealment of one of the fundamental ethical principles - the principle of autonomy¹⁸.

Regarding the information received about the possibility of out-of-hospital additional help, 55% of the sample (11 people) reported not knowing this fact. Only three people (15%) thought they had a lot of information on this subject. Respondents were also asked about information about rehabilitation services, such as physiotherapy and speech therapy services. In all, 85% of the sample (17 people) stated that they had not received any information about the possibility of using these services.

As for aspects directly related to the self-management of the disease, the results were inconclusive, since 25% of respondents reported having little information and the same percentage reported having a lot of information. Regarding the information on specialized psychological support, 40% of respondents said they had not been informed about the subject, even though they later, and in private, turned to the services of this type of professional to adapt to the situation of the disease. Their use of the service was decisive for the self-perception of functional recovery and consequent social and family integration¹⁰.

Concerning the possibility of performing treatments (when appropriate) in different places of care, especially in the outpatient setting, 60% of respondents (12 people) said they had not received such information. Only 10% of the sample (two people) reported they had a lot of information on this subject. The aspects that people can modify to help in the self-management of the disease were another of the applied questions, and it was found that 55% of the sample admits that they do not have information in this area. One should bear in mind some benefits that sick people experience when informed about their illness: 1) greater participation in decision-making; 2) greater satisfaction with the consultation; 3) improvement of the sense of control; and 4) lower levels of affective distress⁹.

Regarding the type of medium in which the information was supplied to the sample, namely when it received written information or on CD or video, 55% said they had received written information. The entire sample reported not having viewed or received information by CD or video. The final questions of the questionnaire were about the information received and the degree of satisfaction with it. Regarding the satisfaction of respondents regarding the amount of information obtained, 40% reported being very satisfied. Only two people (10%) indicated that they were not satisfied with the

information provided by the professionals during the whole disease process.

As for the desire to receive more information, 55% of the respondents said they would like to know more about their situation. This information refers mainly to future treatments and interventions, especially about breast reconstruction, or on the possibility of performing treatments capable of increasing quality of life. However, contrary to what many health professionals may think, patients and their families also want to get more information when the prognosis is not favorable.

Patients and families can face an oncological diagnosis and even understand that the cure is no longer available. However, these findings become more problematic when those affected are not involved in the decision-making process, when information is not clearly communicated to them and decisions are poorly documented. All these aspects undermine the established therapeutic relationship between the professional and the patient, and consequently both decision-making and the free and informed consent, undermining respect for the autonomy of the patient and their right to self-determination in health care.

The desire to have received less information at some stage of the disease was also addressed. Eighteen people (90% of the sample) reported that this did not happen, and only two people (10%) said it had. When questioned about what this moment would have been, they both answered that it was in the communication of the diagnosis, which they characterized as shocking by the excess of information provided. A possible strategy to increase their satisfaction, reduce their psychological problems and help them consolidate or recall the information provided would be the possibility of requesting information, setting the pace, time, or choosing the interlocutors and how they would like the information to be transmitted.¹⁹ Prudent and progressive sincerity should be used instead of the pious lie, transmitting the information to the patients according to their emotional conditions, in a gradual and bearable way²⁰.

Finally, it was asked whether the information received from health professionals had been useful in general. Twelve people (60% of the sample) reported it had been very helpful, and three (15%) said it had been a little helpful. In an area such as palliative care, there are a number of issues to be addressed in the communication process, and as the disease progresses, interests and priorities often change, relating more and

more to concrete aspects of the personal sphere of each patient, which is unique.

The provision of palliative care implies the perception by society, and by health professionals in particular, that patients have their own characteristics and different needs from other groups of the population. Thus, it becomes necessary for health professionals to recover the empathic and compassionate interpersonal relationship as the basis for their conduct. More than technical skills to diagnose and treat, beyond information about the disease and its treatment, people with complex, advanced disease and which threatens the continuity of life expect the relationship with health professionals to be grounded in compassion, humility, respect and empathy. In practice, the implementation and sustainability of these subjective concepts stems from the proper use of communication skills².

Final considerations

Caring for a sick person requires health professionals to individually weigh the circumstances in which, necessarily involving adequate health care, will have to consider the manifestations of their cultural and spiritual values and their affective, familial and social involvement²¹. The results of this study indicate communication deficits between health professionals and people with cancer, with reflexes on free and informed consent and on the patient's involvement in decision-making, and there is still a compromise between power and knowledge sharing between the health professional and the patient.

Quality care is provided by professionals who strive to maintain the dignity of the patient and their caregivers and who work with the patient's strengths and limitations to give them back control and management of their own situation. Likewise, they maintain equity in the ethics of access and location of resources, demonstrate respect for the sick person and his/her caregivers/family, uphold the wishes expressed by the patient, and commit to working for excellence in care and support.

An optimal level of communication determines the establishment of a therapeutic and help relationship, in which real problems and needs of the patient and his/her family are evidenced, which allows the professionals to evaluate the impact of the disease and develop their intervention towards the adaptation to the new reality²². Health professionals need additional training to enable them to establish and conduct the discussion of these issues and to act in such a situation. Although speech is a human attribute, communication techniques are not a natural quality, people are not born with these, they are absorbed in social life and improved by deliberate effort.

In the situation discussed throughout this paper, the possibility of conflicts and impasses increases the fact that communication techniques are not taught persistently in the training during and after graduation in the health area. These skills are addressed only superficially and without systematic training to consolidate them in practice. Effective communication is an indispensable requirement in the process of informing, deciding, consenting and intervening in health care matters. And, just as other practices are trained, communication skills are also exercisable, and due importance should be given to their exercise.

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Participation of the authors

Both authors took part in all phases of the project.

